ACCURATE DATA COLLECTION AND SUBMISSION IMPROVE HIV PLANNING AND DELIVERY

Without the ability to see accurate data, you’re missing out on important care delivery opportunities. You’re missing the whole picture.

—Peter Gordon, M.D.
New York-Presbyterian Hospital and Columbia University

INTRODUCTION AND OVERVIEW
Data, when entered correctly, help tell the story of HIV at the national, community, and individual levels, allowing us to identify and understand disproportionate disease burden and trends as well as inform public health decisions and activities. In fact, the story of HIV/AIDS has always been told through numbers—from the five young, previously healthy gay men in Los Angeles diagnosed with a mysterious disease in 1981¹ to the now nearly 1.2 million people living with HIV/AIDS (PLWHA) nationwide.²

Since the early days of the epidemic, the Health Resources and Services Administration (HRSA) has used data to best target efforts and funds. This was true with the HRSA-led AIDS Service Demonstration Grants of 1986, and it remains true today.

Adequate attention to data collection and submission requirements, particularly client-level data, is critical to curtailing HIV/AIDS in the United States and to improving care access to those in need. Quality data reports that track client demographics, core medical and social services provided, and client outcomes allow Ryan White HIV/AIDS Program providers to pinpoint patients falling out of care, chart a client’s response to a new treatment regimen, and examine the associated costs. Data that are not entered correctly, however, do not represent a reliable picture of services being provided to Ryan White

DID YOU KNOW?
- Encrypted Unique Client Identifiers (eUCIs) are used to protect patient privacy while deduplicating patients.³
- Starting in 2014, the Ryan White HIV/AIDS Program Biennial Progress Reports will feature unduplicated client data.
HIV/AIDS Program clients. These inaccurate data, when submitted to HRSA, hinder National, State, local, and grantee-level public health decision-making and cannot be reliably used. Some steps to improve quality of data are outlined on page 3.

Ensuring that data are correct begins at intake. And the larger the institution and the more providers a patient sees, the greater the likelihood for error. Successful grantees are finding that one way to address this is to collect patient data at every encounter along the way, asking for the patient name (even if this is a patient you’ve seen before) and also the correct spelling. This is a quality management measure that ensures a patient is assigned only one eUCI and all of their visits and lab work are input into the correct record. For example, if their name is misspelled at one intake and correctly spelled at another, this patient would have two “eUCIs” and thus disparate records would be associated with them. Actions can and should be taken to correct this problem prior to client-level data submission.

Similarly, each time a patient comes into the clinic, providers can confirm demographic variables. If this information is incorrect in the system or out of date, providers can immediately modify it accordingly. Making these activities routine and establishing periodic spot checks of the data within your system will go far in ensuring accurate information. This work can inform your retention efforts because patient information is complete, and improve care delivery because a truly comprehensive snapshot of patient information is available. To access additional resources on data collection and technical assistance (TA) in preparing data reports, visit the publications and pages in the “Online Resources” box on page 6.

DATA KEY TO NATIONAL EFFORTS TO STRENGTHEN HIV PROGRAMS

The National HIV/AIDS Strategy (NHAS) is the first-ever national roadmap to reducing HIV incidence; increasing access to care and optimizing health outcomes; and reducing HIV-related health disparities. These NHAS benchmarks are being advanced, in part, through the power of nationwide HIV reporting.

Reporting on the part of Ryan White HIV/AIDS Program grantees, however, can sometimes seem overwhelming. Many grantees receive assistance through multiple funding streams, which may have different data reporting requirements. These may include, along with HRSA, U.S. Department of Housing and Urban Development (HUD), the Centers for Disease Control and Prevention (CDC), Centers for Medicaid and Medicare Services (CMS), Substance Abuse and Mental Health Services (SAMHSA), and others. In total,
This can create a huge burden for data submission on the part of grantees. Federal agencies, however, are working together to better address this, and the NHAS encourages these efforts. If grantees pay attention to the data being submitted and ensure these data are as accurate as possible at the point of submission, this will assist Federal agencies in helping to better streamline data reporting, further the NHAS, and use data to accurately make public health planning decisions.

**THE HIV/AIDS BUREAU’S VISION FOR USING DATA TO IMPROVE HIV CARE**

Today, more than ever, there are opportunities for grantees and providers at all levels to use data to improve their services, better target PLWHA, and ultimately achieve the vision, goals, and requirements of the Ryan White HIV/AIDS Program.

**Maximize the Power of Client-Level Data**
Since the inception of the Public Health Services Act, HRSA’s HIV/AIDS Bureau (HAB) has exercised its public health authority to fulfill its mission to protect the Nation’s health. One way HAB has done this is through a plethora of technical assistance (TA) offerings made available to Ryan White grantees. These include, among others, a data and reporting TA team and a Ryan White data support hot line. Information about these can be found at: www.careacttarget.org/content/ta-providers.

In addition, HRSA has worked to make eUCIs compatible with Ryan White Services Report (RSR)-ready database systems, such as AIDS Institute Reporting Systems (AIRS), Allscripts, AIDS Regional Information and Evaluation System (ARIES), CAREWare, Casewatch Millennium, Capacity Building in HIV/AIDS for Medical Providers system (CHAMPS), eClinicalWorks [2010], Electronic Comprehensive Outcomes Measurement Program for Accountability and Success (eCOMPAS), Labtracker, and Provider Enterprise. Additionally, eUCIs are compatible with general electronic health records and other health information technology. Grantee reporting of eUCI data enables HAB to have an accurate and complete picture of epidemiological shifts and appropriately plan strategies to address such shifts. The same is true for grantees.

For example, like many service areas, the Indianapolis Part A Transitional Grant Area (TGA) treats PLWHA who are transient, in and out of care, or accessing services at different healthcare sites for their myriad health conditions. Because of accurate eUCI data collection, including up-to-date demographic information, the Marion County Health Department was able to see that particular patients were receiving care at multiple sites, resulting in duplications of lab work and ultimately, unnecessary costs and patient burden. Armed with this new knowledge, the Marion County Health Department worked to improve coordination and communication across provider sites, reduce these duplications, and free up funds for other patient care needs. Data led the way in determining where to target these newly available funds for other quality improvements. The end result? Improved understanding of how and where clients were accessing services, and ultimately, a more effective grantee and a healthier community. These patient trends and eventual service delivery improvements were only

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**KEY ACTIONS TO IMPROVING DATA QUALITY OF SUBMITTED CLIENT-LEVEL DATA**

Client-level data are collected through an eUCI, which ensures the privacy and security of clients’ health care information and provides the benefit of linking reports on the same client from multiple providers. To use an eUCI correctly, the following actions must be taken:

1. Assign the eUCI to one person—and only one person—receiving services through the Ryan White HIV/AIDS Program and ensure that the eUCI is being entered correctly. To review the steps necessary to create an eUCI, visit www.careacttarget.org/sites/default/files/fileupload/resources/Guidelines_for_Creating_the_eUCI.pdf.

2. Prior to submitting eUCI data to HRSA, ensure that each data record (or row of data) contains information for one—and only one—person. There should be no duplicate rows of data for the same person.

3. Check that the demographic variables for each person and, thus, each eUCI are up-to-date and correct.

4. Perform periodic checks of client-level data throughout the reporting period to ensure that eUCI, demographic variables, and important core medical services and support services are examined for accuracy and completeness on a small set of Ryan White clients. This is a “spot check” of the data. If results are not satisfactory, then take steps to improve data collection accuracy at the point of data collection. Please use X-ERT or features from some other software packages to periodically review the data set prior to submission to HRSA. Record the steps you’ve taken to ensure continuous quality improvement and enhance communication about data collection efforts.
possible with accurate data submission and tracking. For a visual example of this work, see Figure 1.

SPNS
As Ryan White grantee Peter Gordon, internal medicine and infectious diseases physician at New York-Presbyterian (NYP) and Columbia University explains, “SPNS has been fundamentally important in furthering [data collection] activities. Grantees say they want to improve their data and health information technology systems, and SPNS is creating opportunities to do just that.”

HAB’s support to improve grantee data quality and implementation into health information technology has been extensive. Some recent SPNS research includes the Capacity Building to Develop Standard Electronic Client Information Systems Initiative, which is currently funding grantees under Parts A–D to promote the development of standard electronic client information data systems to improve the ability to report client-level data. The SPNS Enhancement & Evaluation of Existing Health Information Electronic Network Systems for PLWHA in Underserved Communities Initiative (Networks of Care Initiative) promoted and enhanced existing health information electronic networks and improved data reliability.

The Care Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative (Systems Linkages Initiative) is currently funding seven States to translate research into practice for improving State-wide care coordination. One important component of this SPNS work is the sharing of client-level data. Providers across funding streams will be working to improve their data and ability to view patient—and population—health care trends and information across a broader service area than, perhaps, ever before. This work also aligns with the NHAS.

The Massachusetts Department of Public Health (DPH), a Systems Linkages Initiative grantee, is optimistic, particularly that this project will assist in reaching late presenters in their State. As the Massachusetts DPH director of Client Health Services explains, “I really think this work will improve our understanding of who’s falling through the cracks, who are we missing, who is not being adequately served by the entire system—that’s a question we have never been able to fully
answer. And HRSA has asked it, and CDC has asked it. It’s a huge challenge to answer it. This will help us get that.”

A forthcoming SPNS Ryan White Grants Data Reporting Improvement Initiative will assist grantees in improving the gathering, storing, accuracy, and submission of their client-level data to HRSA—just one more example of how HRSA is actively supporting grantees in their efforts to improve the reliability of eUCIs. To read more about SPNS initiatives, visit www.hab.hrsa.gov/abouthab/partfpsns.html and www.hab.hrsa.gov/abouthab/special/spnsproducts.html.

DATA CHANGING CARE ON THE GROUND
Many grantees and providers are utilizing data and data systems as well as data sharing across sites in new, exciting, and promising ways.

HAB Cross-Part Collaborative
“I had an agency that was so proud of their 60 percent viral submission rate—until they learned that the [New Jersey] State average was 70 percent,” says Jane Caruso, project director of the Ryan White Part D Program for the New Jersey State Health Department. Caruso adds,

Without data sharing, the agency never would have broken out of its closed environment or have known that their performance could be better—or that there were fellow grantees who could help show them how. Now, they’re cleaning their data all the time—filling in missing elements and fixing indicators to ensure they’re answering the right questions.

These periodic spot checks and cleanings further the completeness and reliability of their data submissions.

This example underscores the importance of sharing data and how, when grantees work together, data can drive quality. This was, in fact, one of the central tenets of the HAB/National Quality Center (NQC) Cross-Part Quality Management Collaborative (Cross-Part Collaborative), of which Caruso was a part.

The Cross-Part Collaborative brought together Ryan White grantees in five States (Pennsylvania, Connecticut, Virginia, New Jersey, and Texas) to track data indicators as part of a quality improvement project. Each agency in Caruso’s service area used one of four databases: CAREware, CHAMPS, Labtracker, or eCOMPAS to deduplicate patients and look for any errors in the eUCI. If a patient leaves one agency for another, the previous agency will inactivate the patient in the system in an effort to reduce any duplications in the system. All data submitted to the New Jersey Health Department are also reviewed and, as a quality improvement effort, if any data look illogical, impossible, or questionable, the Health Department contacts the agency, discusses the data, and if necessary provides TA to avoid any such errors in the future.

Indeed, the sharing of data—and lessons learned—has proven invaluable. “We transcended geography. . . . I have exchanged tools with Virginia, Pennsylvania, and Connecticut. Other participants built upon lessons learned and sent them back out,” explains Caruso. In these ways, the Collaborative not only created more reliable data systems but improved upon care delivery strategies, too.

in+Care Campaign
The tracking, comparing, and sharing of data is also an important feature of the in+care Campaign, which is HRSA’s first national virtual care campaign. The Campaign is funded and monitored through a cooperative agreement between HRSA/HAB and the New York State AIDS Institute’s NQC and seeks voluntary participation from Ryan White HIV/AIDS Program grantees and providers. The Campaign helps participants track and improve their efforts to retain and reengage PLWHA into care. As the Campaign Web site succinctly notes, “We’re not just measuring outcomes, we’re actively improving lives. After all it’s not data, it’s people.”

Much like the Cross-Part Collaborative, grantees have found it immensely helpful to broaden their peer network in order to share best practices and also to compare their programs with others as a way of measuring their successes and, together, working toward improvements.

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Programs are compared using aggregate, self-reported data which they input into a custom database. Since sites are comparing their performance—and room for improvement—against others, they can only get an accurate assessment if they submit accurate data; thus, it’s in their best interest to do so. For example, Campaign participants are able to compare themselves against other similarly funded grantees, those in their region, and against the national average, as well as the Campaign’s top 10 percent and top 25 percent of performers.

To help make this happen, the Campaign has assigned “quality coaches” to support all participants with unduplicated, accurate eUCI reporting as well as interpretation of data. For those grantees in greater need, the Campaign has established “database champions” specialized in a variety of electronic health records and electronic databases to help sites with processes and collection. Database champions also assist grantees in extracting and synthesizing their data into reports. If, in spot checks, grantees come across data that need updating, they can readily do so and resubmit Campaign reports.

HRSA/HAB and NQC have also been cognizant of the need to share retention in care research with participants to further inform their efforts. One such example includes the Giordano
study, which found that patients who attended all medical appointments during the first year of HIV care doubled survival rates for years afterward, regardless of baseline CD4 cell count or use of antiretroviral therapy (ART). According to numerous Campaign participants, the data from this study have encouraged them to create more intensive interventions in a patient’s first year of care, including increased patient education and dedicated time to patients during this window.

**Paterson, New Jersey: Use of eCOMPAS**

Jesse Thomas is project director of the eCOMPAS program—a system that enables contract and financial management, quality improvement, client satisfaction surveys, and eUCI capabilities. The program eCOMPAS is compatible with HAB, Housing Opportunities for People With AIDS, and HIV prevention program data submission requirements. As part of the SPNS IT Initiative, the city of Paterson, New Jersey, implemented eCOMPAS and utilized its computer-based client survey system.

The survey system, which offers multilingual, low health literacy, and audio computer-assisted self-interview options, provided anonymous, real-time feedback to providers about the quality of their care and offered insight where they needed to make changes. Catherine Correa, who until recently served as the director of the Ryan White Grants Division for the City of Paterson Department of Human Services, notes that “clients could say ‘I would rather go to this hospital than this hospital’ and why. It really allowed providers to gauge how their clients were thinking and feeling, so that they could help improve adherence and care retention.”

As Thomas explains, “SPNS was years ahead of the game, funding initiatives on how a system could serve as an intervention to improving care, particularly as it relates to the sharing of health information…making a difference in people’s lives.” Thomas recalls how data captured from computer-based surveys showed a decrease in client satisfaction with a provider. A closer look at the data showed that the dissatisfied clients were almost universally mothers caring for young children. The provider noted that these clients probably were upset with recent changes in their hours of operation. The feedback prompted the clinic to set hours more amenable to mothers who needed to take children to school, and its client satisfaction levels increased.

“This story offers an example of data making a difference. Here, patients are telling providers what it takes to have them be adherent to their appointments and stay engaged in care—create more hours of operation that work for parents,” says Thomas. “Rather than researchers telling them what to do, the provider itself looked at the data and adjusted its course of action.” In this way, data are assisting providers in better targeting their approaches, improving retention, and, ultimately, improving patient care receipt.

The eCOMPAS system also encourages patient verification every time data are entered, as a means of ensuring accurate data input. The program, however, offers an additional
and unique way to further spot check patient information in provider databases: Patients can be given access to their own information as a way to ensure there is no duplication of records for them. Patients can check for mistakes, mispellings, and out-of-date information, and can also flag tests or other clinical information they have questions about. In this way, patients and providers are working together to take steps toward improving data accuracy and submission, health-care communication, transparency, and care delivery.

**New York-Presbyterian Continuity of Care Record**

NYP, through the Networks of Care Initiative, ramped up its electronic health information network. Providers, as well as PLWHA themselves, are able to securely access client information online through Continuity of Care Record (CCR): a standard snapshot of very critical demographic, and clinical and care coordination information.

So, for example, if a patient is applying for housing assistance and needs to demonstrate HIV positive status, they can bring their information up on a computer and immediately continue with the admissions process to receive this critical social support. Similarly, a patient admitted to the hospital can provide their physicians with their CCR passcode and access to their record. This will show their physician their most recent lab work and medications, thus avoiding medication interactions or antiretroviral interruptions.

As Peter Gordon of NYP says,

> One of the things that certainly contributes to the fractionation of care and discoordination of care are these silos of clinical information that exist in different care sites and social service agencies. [W]e asked the question of whether or not we could put that power in the hands of consumers. What we found was that people were eager to be trained…for some individuals it was the first time they had ever sat down at a computer terminal and opened up a browser. [They] were quite liberated, not just by learning how to access their medical record, but also how to take that access and use it to promote a sort of self-efficacy and [an] understanding of the chronic illnesses they had been diagnosed with [and] medications they had been prescribed. The SPNS grant demonstrated that vulnerable populations with marginal health literacy will adopt a personal health record at rates similar to more affluent, more educated populations.

When SPNS added an additional funding year, NYP began to utilize—much like the City of Paterson—the eCOMPAS system. Specifically, eCOMPAS was integrated into the current health information system to increase data capabilities. For example, with eCOMPAS NYP was able to implement an algorithm to autocorrect patients’ provider point of contact to match with the provider who performed the last two HIV patient tests. So, for example, if a non-HIV provider is seeing a patient for another health care issue and needs to confer with the HIV primary care doctor, they can readily access this accurate and up-to-date information.

Similarly, providers can now see population data not only on an individual but across patients. “If your system can’t print out a report on your population, you’re missing something critical,” says Gordon. “We didn’t replace our IT system, we asked what can’t it do and how we could try to achieve this through eCOMPAS.”

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NYP has multiple funding streams, so having a system in place that enables Gordon to hit a button and submit a report to HRSA, another button and send data to State funders, and so on, frees up time to dedicate to direct patient care, and Gordon feels confident that the data submitted are dependable. This allows HRSA to do their part in public health planning.

**GRANTEE LESSONS LEARNED**

**Focusing on One Issue at a Time**

As Thomas explains, “Focusing on just one quality [data] improvement measure gets people comfortable with tracking performance, studying the results, and then taking action to start the cycle over again for further improvement.”

**Creating Community and a “Safe Space” for Feedback and Learning**

Ensuring that grantees have input into the process creates a sense of trust. The DC collaborative held regular Learning Sessions—2-day events during which grantees reported on their current activities; heard lectures on topics such as health screening and syphilis; and openly discussed challenges that kept the collaborative from reaching its goals. Challenges included helping grantees increase their comfort and understanding of data collection.

**Sharing Only De-identified Data Among Grantees**

The collaboratives found that grantees were much more likely to submit clean, truthful data if they were assured that the data would remain anonymous. Grantees and their providers wanted the option of privately addressing issues that kept them from performing as well as their peers.

**Allowing Clinical Staff Access to Client Data**

Efforts to improve care through data sharing empowered...
more clinical staff to participate. In addition, increasing phy-

Attention to Data Collection and Submission
Grantees with successful data collection and submission recognize that data are only as helpful as they are accu-
rate. If data are dependable, then they can illustrate what patients are accessing care, who is falling out of care, what services are being utilized, what the associated costs are, where public health trends are emerging, and a multitude of other important issues. Armed with this information, grantees can best develop a game plan of how to move forward and where to target their efforts. The landscape of HIV care and planning is changing, and the grantees highlighted in this newsletter illustrate that keeping up means keeping clean data systems.

CONCLUSION
There are myriad ways to track data—and to make data work for you. For HAB to be most informed, the eUCI must be used consistently and the eUCI must be correctly collected and sub-
mitted. For strategies to do so, see the “Key Actions to Improving Data Quality of Submitted Client-Level Data” box on page 3.

By giving appropriate attention to adequate data, grantees can inform public health efforts not only today, but well into tomorrow. These efforts ultimately mean more coordination and improved quality of care—and quality of life—for people with HIV/AIDS. And with improved quality comes a brighter and better future.

REFERENCES

3 Guidelines for creating the RSR encrypted unique client identifier (eUCI). Created by SPHERE Institute under cooperative agreement with HRSA, HAB. 2010. Available at www.careacttarget.org/library/Guidelines_for_Creating_the_eUCI.pdf.
6 in+care Campaign. About the campaign: Learn more about getting involved. www.incarecampaign.org/index.cfm/75262.